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Barriers to medical help-seeking among older men with prostate cancer

Medina-Perucha, L.¹, Yousaf O.², Hunter M.S.³, & Grunfeld E.A.⁴

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1 Department of Pharmacy and Pharmacology, University of Bath, UK

2 Department of Psychology, University of Bath, UK

3 Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

4 Centre for Technology Enabled Health Research, Coventry University, Coventry, UK

Corresponding author

Laura Medina-Perucha

Department of Pharmacy and Pharmacology

University of Bath

5 West, 2.52

Bath, BA2 7AY

E-mail: l.medina.perucha@bath.ac.uk

Phone: +44 (0)1225 384215

Abstract

Objective. Men's disinclination to seek medical help has been linked to higher rates of morbidity and mortality compared to women. However, previous studies were conducted predominantly with healthy, young, and middle-aged men. We explored the perceived medical barriers to help-seeking in older men with prostate cancer. **Method.** Twenty men with prostate cancer took part in semi-structured interviews, which were analysed using thematic analysis. **Results.** Three themes were identified related to negative attitudes towards help-seeking: male gender role; fear of the health condition, medical and treatment procedures; and embarrassment as a consequence of medical examinations, communication with health (and non-health) professionals, and the disclosure of sexual-related symptoms. **Conclusion.** The barriers identified in our study strengthen the evidence for the impact of the traditional masculine on help-seeking in men.

Key words: help-seeking, men, prostate cancer, masculinity, thematic analysis

Introduction

The adoption of traditional male role norms has been associated with unhealthy behaviours such as poor diet (Gough & Conner, 2006), smoking, excessive alcohol consumption (De Visser, Smith & McDonnell, 2009), and a higher risk of injury (White et al., 2011). Masculine roles have been also identified as significant factors for the non-use of or delay in accessing the healthcare system (Cusack, et al., 2006; Doherty & Kartalova-O'Doherty, 2010; Galdas, Cheater & Marshall, 2005; Hale, Grogan, & Willott, 2010; Johnson, et al., 2012; Levant, Wimer, & Williams, 2011; McCusker & Galupo, 2011; Möller-Leimkühler, 2002; Wenger, 2011; White et al., 2011; Yousaf, Grunfeld & Hunter, 2013; Yousaf, Popat & Hunter, 2014). In addition, when compared to women, men are more reluctant to seek medical and psychological professional advice (Cusack, Deane, Wilson, & Ciarrochi, 2006; Doherty & Kartalova-O'Doherty, 2010; Hale, Grogan, & Willott, 2010; Levant, Wimer, & Williams, 2011; Johnson, Oliffe, Kelly, Galdas & Ogrodniczuk, 2012; McCusker & Galupo, 2011; Möller-Leimkühler, 2002; Wenger, 2011; White et al., 2011; Yousaf, Grunfeld & Hunter, 2013; Yousaf, Popat & Hunter, 2014). Failing to seek medical

assistance in a timely fashion has been linked to increased mortality rates, and the deterioration of medical conditions (Hale, Grogan & Willott, 2010; Yousaf, Popat & Hunter, 2014). Recent reviews by Yousaf, Grunfeld & Hunter (2013), and by Fish, Prichard, Ettridge, Grunfeld & Wilson (2015) aimed to identify the barriers for men to seek medical help promptly. Psychological and contextual factors were linked to men's underutilization of health services. The most salient were the need for emotional control; embarrassment, anxiety, fear and distress regarding utilising healthcare services; viewing symptoms as minor and not significant; and perceptions of poor communication and rapport with health professionals.

Prostate cancer is the most common cancer amongst men (NHS, 2015; World Health Organization, 2014), and a leading cause of cancer-related death worldwide (World Health Organization, 2011). Men with prostate cancer present with symptoms (e.g., urinary tract-related ones) that could be attributed to non-cancer disease or to ageing. Besides, although experiencing such symptoms has an impact on men's lives, these are not seen by some men as sensible reasons to consult their doctor (Cunningham-Burkley, Allbutt, Garraway, Lee, & Russell, 1996). Previous research by George and Fleming (2004) looked at the factors impacting help-seeking in early detection of prostate cancer. Twelve men who had attended a charity-based service for the early detection of prostate cancer in the last three months were interviewed. Men in this study emphasised the importance of the generalised negative views and fear of cancer as main barriers to seek help. Moreover, speaking and seeking medical advice was identified with a perceived loss of masculinity, and a feeling of embarrassment. Men's low somatic awareness, and health professionals' lack of interest and proactivity were other help-seeking barriers identified. Age and the increasing media coverage of prostate cancer were positively associated with a raise in awareness and intentions to seek medical advice. Moreover, recent research has found relationships to be pivotal in informing and facilitating men's help-seeking behaviour for prostate cancer symptoms (Forbat, Place, Hubbard, Leung, & Kelly, 2013). However, further research is needed to determine the barriers for help-seeking for prostate cancer.

However, the majority of studies looking at help-seeking in men have focused on healthy individuals (Yousaf, Grunfeld & Hunter, 2013; Yousaf, Popat & Hunter, 2014). Yet, it essential to understand the barriers to seeking medical attention from those individuals who

have already sought medical help, been diagnosed, and received medical treatment (George & Fleming, 2004). Determining such factors could not only improve our understanding of the help-seeking barriers in men, but have implications for health promotion and disease prevention programmes. For instance, identifying help-seeking barriers among men with prostate cancer may help designing effective and relevant health promotion programmes and ensure the design of healthcare services that promote engagement. Previous research, has highlighted the difficulties of maintaining a culturally accepted gender role in ageing men, given that health deterioration may be perceived by men as compromising their masculinity (Rochelle, 2015; Spector-Mersel, 2006). This could further contribute to the low rates of help-seeking in men in order to preserve their masculinity.

On the other hand, despite the importance of including older men in help-seeking research, few studies have been conducted with men aged over 60 years (Yousaf, Grunfeld & Hunter, 2013). Examining the factors and barriers to help-seeking in older men is particularly relevant to explore the reasons of the lower rates of help-seeking observed in older men (National Institute on Aging, 2007). This could lead to improvements in health services and health promotion efforts for older men, earlier detection of prostate cancer and other health conditions, more positive health outcomes, and have an impact on quality of life and life expectancy in men (Office of National Statistics, 2014).

The present study, aims to further explore the barriers for help-seeking in older men with individuals who have been diagnosed and have undertaken treatment for prostate cancer.

Method

Participants

Participants were recruited from the treatment arm of the MANCAN trial following the final assessment. The MANCAN (from “*man can*”) was a randomised controlled trial of guided self-help cognitive behavioural therapy compared with the usual treatment (Stefanopoulou, et al., 2015). From the 68 male participants in the MANCAN trial (treatment arm only) that were approached to participate in the study, 20 (29%) agreed to take part.

The men ranged in age from 57 to 83 years ($M = 69$) and categorised themselves as either White British ($n = 18$) or Black British ($n = 2$). Over half were retired (55%) at the time of the interviews. Fourteen of the men had localised prostate cancer (70%), while six had locally advanced prostate cancer (30%) (see Table 1).

Procedure

Ethical approval was obtained through the local Research Ethics Committee (11/LO/1114). An explanation about the purpose of the interviews was given prior to the patients' participation and written consent was obtained from each participant. Semi-structured interviews were conducted after the 6-month follow-up assessment following the MANCAN trial [on average, 35 weeks after recruitment into the trial (range = 28 to 65 weeks)]. The interviews were conducted independently of the trial by a researcher (OY), blind to the patient outcomes. All the interviews took place between November 2012 and May 2014, at Guy's Hospital in London. The majority of the interviews were conducted with patients individually, however three were conducted with the patient/spouse dyad. None of the contributions by the spouses were included in the analysis of the data.

The interview was divided into two parts; the first part explored participants' experiences of the MANCAN trial, and the second half focused on help-seeking and explored perceptions of their own medical help-seeking and beliefs about help-seeking among men more generally. Interviews were taped and transcribed verbatim, and ranged in duration between 10 and 52 minutes ($M = 29$). Accuracy of the transcripts was checked against the original recordings. Each participant was assigned a pseudonym to maintain confidentiality. The data from the present study is based on one question that focused on barriers that men face when seeking medical help, concerns about the help-seeking process, and participants' own experience of help-seeking for prostate cancer.

Analysis

All interviews were analysed by LMP using an agreed framework that identified potential themes in the data by OY and EAG, based on the Braun and Clarke's approach to thematic analysis (2006). Throughout the analysis process, the authors discussed and revisited the

original framework and collectively identified the superordinate themes to have emerged from the analysis.

Thematic analysis was used to identify, analyse, and report patterns (themes) within data. Inductive latent level analysis was applied, so that the exploration of the data went beyond the participants' explicit answers. The thematic analysis step-by-step guide by Braun and Clarke (2006) was used to analyse the data. These steps were: 1) Familiarization with the data, which included a "repeated reading", searching for meanings and patterns on the data prior to the generation of codes. An initial list of ideas about the data was generated; 2) Generation of initial codes, as an initial organisation of the data. It consisted in identifying patterns in the data and potential themes, including the context of such patterns; 3) Search for themes, which involved combining the codes from phase 2 into themes and sub-themes; 4) Revision of themes to refine the ones identified in the previous phase; 5) Definition and naming of themes that captured their essence; and 6) Final analysis and report write-up.

Results

Three main themes were identified: male gender role, fear, and embarrassment.

Theme I. Male gender role: limited emotional expression, need for independence and control, and minimisation of symptomatology as barriers to seek medical help.

Most men considered the traditional male gender role as a main barrier to seek medical professional help. The male gender role theme included restricted emotional expression, the need for independence and control, and viewing symptoms as minor and insignificant.

Men's need for independence and control, as well as the potential threats to the male gender role were associated to the low rates of help-seeking behaviour in men.

'Machoism isn't it really...? It's... tough guys don't need help' (Participant 5)

'It is probably the male thing isn't it sort of like I am a bloke, I am okay, it is not going to happen?' (Participant 16)

'The treatment is emasculating. Not only physically, but I think there must be a psychological emasculating, and I don't think that many men are able to cope with that' (Participant 8)

Difficulties in communicating and expressing emotions were related to reluctance in seeking help-seeking.

'Because of this image...the male image (...) men are very reluctant to discuss emotional problems, even with their close friends' (Participant 4)

'Men aren't good at communicating sometimes. I think communications can be a, especially in certain problems...' (Participant 15)

In addition, participants expressed men's propensity to minimise the significance of medical symptoms as a reason to avoid or delay seeking professional help.

This was linked to the increased tendency of men to deal with health-related problems without consulting healthcare professionals.

'Well, maybe they just think that they are so masculine that nothing can go wrong with them, you know, they have that sort of inbuilt feeling....macho type of person. 'I'm not going to the doctor's, there is nothing wrong with me'. Putting it a bit simply, you know' (Participant 6)

'I was in perfect health. I would never go desperately, like a lot of people go for the smallest thing don't they?' (Participant 6)

Theme II. Fear: distress as a limitation for help-seeking behaviour.

Fear was also identified as a main barrier to engage in help-seeking behaviours by many men.

'They're scared. Men are generally scared about their health, aren't they?' (Participant 11)

Fear was associated with the actual health condition, and also the medical procedures including screening and treatment processes.

'I found it's more of a worry waiting for the results of the tests than it is actually taking the tests themselves (...) but it is a big shock, being diagnosed with anything...'
(Participant 6)

Theme III. Embarrassment: threat of privacy and masculinity as barriers to help-seeking behaviour.

Some men reported embarrassment as a main barrier for seeking professional medical advice. Sources of embarrassment were identified to be sexual-related symptoms, medical examinations, and communication with health (and other) professionals working in the healthcare system. Both medical exams and expression of sexually-related symptoms were associated with a violation of men's privacy and masculinity.

Anticipation that they might be exposed to such situations was identified as an important reason for the lack of help-seeking behaviour by the men.

'Something that he has found very very difficult, and he hasn't told his doctor yet, he finds it unbearable that he no longer has any sex.....but I think personally for him or mentally, that was very difficult to come to terms with.(...) I doubt that they even talk to their partners about it' (Participant 8)

'I think the problem with men is that it's the initial examination (...) My doctor is a woman doctor and she said we have to examine you, so the pride thing (...) Invasive, that's the word' (Participant 18)

'The receptionist asks you what you want to see the doctor about. Well, I'm not going to tell her I can't get an erection, am I? I don't think they should do that. It's embarrassing enough, but to tell a receptionist why you want to go and see a doctor for. I would never tell her' (Participant 13)

Apart from the themes identified in relation to barriers to help-seeking, other patterns in the data were identified. These were men's awareness of timely help-seeking, the non-identification of personal help-seeking delays, and generational differences.

Some men mentioned having gained awareness of the importance of timely help-seeking since they experienced, or someone close to them experienced, a major health problem. In fact, a few men considered major health problems, such as prostate cancer, to be turning points in their lives that prompted them to change their attitudes towards help seeking, and even to promote cancer screening in other men. Besides, most men did not identify themselves as delaying help-seeking. However, they considered that the majority of men, i.e. other men, were reluctant to attend medical services. Generational gaps were as well identified. Some men mentioned generational differences to have an important role in help-seeking behaviour variances within men. Specifically, they suggested that males from older generations are often more reluctant to seek medical help, compared to younger men. The potential reasons for these variations amongst generations were believed to be educational and societal differences.

Discussion

This study aimed to explore the perceived barriers to seeking medical help in older men with prostate cancer. The participants were twenty males diagnosed and treated for prostate cancer, and were part of the MANCAN trial (Stefanopoulou, et al., 2015). Barriers to help-seeking identified included adherence to the traditional male gender role, fear and embarrassment. Awareness of timely help-seeking, non-identification of personal help-seeking delays, and generational gaps were other additional findings in this study. Although important, these additional findings were not considered as main themes in the present study. These findings were generally consistent with previous research that has focused on help-seeking amongst younger men (Davis & Liang, 2015; Fish, Prichard, Ettridge, Grunfeld & Wilson, 2015; Hoyt, 2009; O'Neil, 2008; O'Neil, Helms, Gable, David & Wrightsman, 1986; Yousaf, Grunfeld & Hunter, 2013; Yousaf, Popat & Hunter, 2014).

The traditional male gender role (Theme I) was characterised by men's reluctance to emotional disclosure and the need to portray themselves as strong and resilient. Social

expectations were consistently identified by the participants as the main reason for subscribing to the traditional male gender role. Indeed, it has previously been suggested that masculine gender-role socialization is a plausible explanation to understand men's, at times, non-adaptive help-seeking behaviour (Addis & Mahalik 2003). Seeking medical help implies relying on others, admitting one's needs, and the acceptance of a diminished health status. However, these processes may cause a conflict in some men who value the importance of being self-reliable, physically tough, and emotionally in control (Good, Dell & Mintz, 1989; Yousaf, Grunfeld & Hunter, 2013). Previous literature on masculinity, based on a social constructionist perspective, has focused on two main constructs, masculinity ideology and gender role conflict. The first accounts for men's internalisation of cultural norms and values regarding masculinity and the male gender role (Addis & Mahalik, 2003; Courtenay, 2000; Mahalik, Burns & Syzdek, 2007). The second focuses on the negative cognitive, emotional and behavioural consequences associated with the traditional male gender role (Hoyt, 2009). The gender role conflict has a significant impact on men's health and wellbeing (Davis & Liang, 2015; O'Neil, 2008), and has been associated with negative attitudes towards help-seeking (Blazina & Watkins, 1996; Davis & Liang, 2015; Good, Dell & Mintz, 1989; Good & Wood, 1995; Steinfeldt, Steinfeldt, England & Speight, 2009; Yousaf, Popat & Hunter, 2014). As the findings of the present study suggest, men may be reluctant to seek help from health professionals because they perceive such behaviour as a threat to their social and personal identity. Previous research has, indeed, identified the tendency in men to avoid self-care in the context of injury, as it is a social sign of strength and masculinity (Addis & Mahalik, 2003).

Most participants in the current study acknowledged men's tendency to underutilise the healthcare system, however, the participants did not express a personal inclination to avoid or delay help-seeking. This finding could be explained by the conflict most men experience between conserving their traditionally masculine social role and their realisation that it is more beneficial to seek help. Gough (2006) raised awareness about the importance of not assuming all men are unlikely to seek professional assistance, but of empowering men to act beyond the social expectations of gender specific behaviours. On the other hand, it is important to note that this study did not aim to determine whether there is an actual delay in help-seeking among men with prostate cancer. Therefore, it can only be concluded that there is a perceived delay in seeking help. Previous research has looked at the differences in help-

seeking delays between different types of cancer (breast, prostate and colorectal) (Emery et al., 2013). Emery et al (2013) found longer total diagnostic intervals (which included symptom appraisal and help-seeking behaviour) in individuals with prostate and colorectal cancer, compared to breast cancer patients. While this was not the aim of the present study, future research should further explore and quantify the delay in help-seeking among cancer patients in order to determine the delays in seeking medical assistance.

In order to promote engagement with health services, future research should further investigate the determinants of help-seeking in diverse groups of men (e.g. social class, ethnicity, age, or sexual orientation), as well as to investigate more homogeneous men with varying lifestyles (e.g., single versus married men). Moreover, the delivery of men's health promotion could be made more wide-ranging, for example, via education (Demyan & Anderson, 2012), the media (Gough, 2006) and workplace health programmes (Dolan, Staples, Summer & Hundt, 2005).

Fear (Theme II) was associated to distress and worry resulting from screening procedures (i.e. digital rectal examination), being diagnosed with a serious health condition (such as prostate cancer), and negative experiences with health professionals. In addition, most men mentioned men's tendency to avoid seeking medical help and thereby remaining unaware of their health status. This theme was to some extent related to the distress that may result from a diagnosis of prostate cancer, screening procedures (i.e. digital rectal examination), and sexual symptomatology associated with prostate cancer, which may be perceived to jeopardise men's gendered identities. Psychological distress has been found to be associated not only with delayed help-seeking (Cepeda-Benito & Short, 1998; Cramer, 1999; Demyan & Anderson, 2012) but also with greater fear towards medical treatment and with lower normative perceptions (i.e. the perception that few men actually seek treatment) (Demyan & Anderson, 2012). However, the nature and direction of the relationship distress and help-seeking behaviours in men remains unclear (Demyan & Anderson, 2012; Kelly & Achter, 1995; Vogel & Wester, 2003; Vogel, Wester, Wei, & Boysen, 2005). Further exploration of the relationship between fear, distress and help-seeking is required with greater focus on avoidance behaviours, rather than merely attitudes and intentions (Demyan & Anderson, 2012).

Embarrassment (Theme III) was closely related to Theme I and II, and associated with receiving a diagnosis, medical procedures, the disclosure of symptomatology, as well as the utilization of the healthcare system. Perceived stigma and social expectations for men to behave according to their gender role strongly determined the experience of embarrassment in men to seek medical professional assistance for prostate cancer. Men with prostate cancer may be more likely to report embarrassment, for example due to the body localization of the condition, diagnostic procedures (i.e. digital rectal examination), and high rates of post-treatment sexual dysfunction, all of which may increase embarrassment. Negative attitudes, embarrassment and discomfort towards digital rectal exams for prostate cancer diagnosis have been reported to be associated with avoidance of screening (Ferrante, Shaw & Scott, 2011). In addition, sexual dysfunction is reported to be the most significant and long lasting effect of prostate cancer treatment (Beck, Robinson & Carlson, 2013; O'Shaughnessy, Ireland, Pelentsov, Thomas & Esterman, 2013). Consequently, directing efforts to reducing perceived or actual social stigma towards prostate cancer and masculinity, not only in men but in the general population, could have an impact on the rates of help-seeking in males. Reducing self-stigma could increase the intentions to seek help (Vogel, Wade, & Haake, 2006).

One limitation of the present study is the lack of questions on the role of socio-demographic, structural and intrapersonal factors in the help-seeking process. In addition, although most participants acknowledged men's general tendency to delay or avoid seeking medical help, the participants did not identify themselves as being part of this group of help-seeking averse men. An explanation for this may be that the individuals in this study were self-selected and may have held more positive attitudes towards help-seeking as they had volunteered to be part of a research trial. Another potential explanation is that men in this study may not identify themselves as delaying help-seeking due to the retrospective nature of the research, which could have hindered recalling past events. Further research could compare the perceived delay with the actual delay in seeking medical assistance.

On the other and, the main strength of this study lies in its focus on older men, which is an underexplored group within the help-seeking literature. The study provides evidence that masculinity values, fear and embarrassment are associated with reluctance to seek

medical help among older men and these themes are similar to those reported among younger men.

In terms of implications, health professionals need to empower their patients so that they feel enabled to seek help and undertake medical procedures (George & Fleming, 2004; Kravitz, et al., 2011). General perceptions of healthcare services may be improved through facilitated, shared decision-making (Ferrante, Shaw & Scott, 2011; Jalil, Ahmed, Green & Sevdalis, 2013; Leader et al., 2012) and improvement in the training of healthcare professionals. Doherty & Kartalova-O'Doherty (2010) suggested that the 'gender sensitive approach' should be implemented in the healthcare system; an approach which acknowledges factors that influence help-seeking so that gender specific promotion, prevention and treatment programmes can be implemented. Besides, mass media and educational campaigns should be improved and adapted for men of all ages (Demyan & Anderson, 2012; Ferrante, Shaw & Scott, 2011; George & Fleming, 2004). Despite the relevance of studying contextual factors, most studies solely focus on the role of gendered attitudes and behaviours. Future research should incorporate the analysis of contextual and social factors, such as characteristics of the healthcare system or employment status, in order to be able to shape a broader perspective about help-seeking in men. In addition, researchers should direct their attention on the impact of mediators and moderators in the relationship between masculinity and men's negative help-seeking attitudes (e.g. self-stigma), rather than exploring factors individually (Levant et al., 2013).

The findings have potential to inform health promotion programmes, challenging stereotypes and developing ways to reduce embarrassment and fear in relation to help-seeking in men for prostate cancer.

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Table 1: *Participant characteristics*

| | |
|------------------------------------|---------------|
| Mean age (years) | 69 (57 to 83) |
| Work status | |
| Full-time | 3 (15%) |
| Part-time | 3 (15%) |
| Self employed | 3 (15%) |
| Retired | 11 (55%) |
| Marital status | |
| Married | 18 (90%) |
| Single/divorced | 2 (10%) |
| Ethnicity | |
| White | 18 (90%) |
| Black/Black British | 2 (10%) |
| Cancer classification | |
| Local | 14 (70%) |
| Locally advanced | 6 (30%) |
| Type of ADT | |
| Bicalutamide casodex | 2 (10%) |
| Cyproterone Acetate | 1 (5%) |
| Zoladex | 16 (80%) |
| Triptorelin Decapeptyl | 1 (5%) |
| Mean time since diagnosis (months) | 29 |
| Mean period on ADT (months) | 19 |

Note. ADT = Androgen Suppression Therapy